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ABSTRACT

The report discusses financing respite care (short term care of the handicapped to provide family relief) services for the developmentally disabled (DD). Respite care is examined as a component of a comprehensive service delivery system for the DD, and the scope of respite care services as conceptualized by its advocates is reviewed. Nationally recognized taxonomies of services for the DD generally emphasize respite care as a temporary living arrangement component of an individual and family support service, although certan advocates of respite care have suggested that it be viewed as a comprehensive supportive family services network. Many states are developing respite care programs which may be viewed as one component of a family support network. The nature of federal funding and the classification of services are examined. The financing of respite care models is discussed in terms of out of home residential placement, out of home family placement, in home health and attendant services, in home sitter and companion services, family support services, and respite care as day activities. Also discussed are start up and core staffing of respite care programs. (Author/DLS)

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RESPITE CARE AS A COMPONENT OF A COMPREHENSIVE SERVICE DELIVERY SYSTEM

Before one can present suggestions on sources of financing for respite care, one has to define respite care and offer a conceptual framework of how it relates to a more comprehensive service delivery system.

Numerous taxonomies of services have been developed over the years. Since this respite care project is being funded by the national Developmental Disabilities Office (DDO), this writer will rely on two recent taxonomies - one by Governmental Studies And Systems (1977, funded by DDO) (1) and the other by the National Association of State Mental Retardation Program Directors (1979, funded by the President's Committee on Mental Retardation)(2).

The GSS taxanomy of services contains five major service areas - prevention and detection services, individual program planning and case management, developmental services (e.g., skills development, habilitation, and therapy), support services (discussed below), and generic services (e.g., medical services, dental services, and education).

The GSS support services area contains a category titled individual and family support services which includes advocacy services, protective services, counseling, family education and training, respite care, and transportation. Respite care, as one of a series of individual and family support services, is viewed primarily as a short term alternative residential placement.

The NASMRPD report is based on 82 state mental retardation officials in 47 states (providers) respondents and 63 Association for Retarded Citizens officials in 35 states (consumers) respondents to survey material. The surveys sought to determine (1) what a minimal service array (i.e., essential services as opposed to non-essential services) is, and (2) how to cluster needed services into logical categories of service areas.

NASMRPD respondents were asked to sort a deck of cards containing 49 service descriptors into related categories of services. Providers grouped services into 11 categories while consumers grouped services into 12 categories. Two of the 49 services were "respite care," defined as "the provision of residential services on a short-term basis to alleviate situations created by family emergencies, vacations, or other temporary needs," and "sitter services," defined as "in-the-home care for the temporary relief of the family."

The grouping of service areas by both providers and consumers follow:

Service Grouping By Providers	Service Grouping By Consumers
1) Education	1) Education
2) Advocacy and Protective Services	2) Advocacy and Protective Services
3) Vocational Services	3) Vocational Services
4) Health Maintenance	4) Health Maintenance

5) Family Support Services
   Family Counseling
   Family Training
   Parent Education
6) Individual Planning And Management
7) Transportation
8) Self-Help Skills
9) Fixed Point Of Referral
10) Adaptive Living Arrangements
   Sitter Service
   Respite Care
   Homemaker Service
   Adaptive Housing
11) Social Skill Developments
   Includes Family Life
   Education And Counseling

5) Family Support Services
   Family Counseling
   Family Training
   Parent Education
6) Parent Relief
   Respite Care
   Sitter Services
7) Self-Help Skills
8) Transportation
9) Fixed Point Of Referral
10) Individual Development
11) Individual Planning
12) Social Development And Maintenance
   Includes Homemaker, Adaptive
   Housing, and Family Life
   Education And Counseling

Both respondent groups classified related services which generally are the focus of federal assistance programs (education, rehabilitation, and health) into highly cohesive categories. By contrast, the least stable categories (social skills development, adaptive living arrangements, and self-help skills) were those which are most difficult to relate to any single federal funding stream. Thus, respondents were more likely to agree on the clustering of services into any particular category if there was some uniformity in administrative structures and funding streams superimposed by the federal government.

As a result, providers view respite care as a component of adaptative living arrangements while consumers viewed it as part of parent relief. Nationally, respite care remains generally undefined without uniformity.

NASMRPD respondents also rank ordered the 49 service areas in order of priority. Rankings for the areas related to respite care follow:

Area	Provider Ranking	Consumer Ranking	Cumulative Rank Order
Adaptive Housing	14	21	14
Family Training	24	28	21
Respite Care	20	43	23
Family Life Education And Counseling	35	42	41
Family Counseling	31	49	44
Parent Education	42	37	45

Sitter Service	47	20	47
Homemaker Service	48	41	48

The minimal service array (i.e., essential services) were defined as the first 17 priority service areas. Of all the areas cited above as related to respite care, only adaptive housing is included as an essential service. There was virtually total agreement about the relative importance of assessment, training in self-care, and training in independent living skills.

One final nationally recognized way of looking at respite care in relation to the larger service delivery system is the classification of services used by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (1977, AC/MR-DD)(3). The standards contain a major section on alternative living arrangements which includes (1) "homemaker and sitter/companion services," defined as "in-home services provided to enable developmentally disabled individuals to remain with their families or in their own homes;" (2) "temporary-assistance living arrangement," defined as "those components of the alternative living arrangement services network that provide primarily short-term, in-or out-of-the-home care of a developmentally disabled individual for the temporary relief of the individual or the family, or in times of crisis;" and (3) "surrogate family services," defined as "substitute family homes under contractual arrangements between surrogate families and the placing agency."

Another major section of the AC/MR-DD standards is individual program support which includes a subsection on "family-related services." This subsection includes "home training services," defined as "specialized training programs for the individual and/or the family that are primarily conducted within the home" and "family education services," defined as "opportunities for the individual's family to increase its knowledge of developmental disabilities and its understanding of other concerns relating to the family unit."

Thus, three nationally recognized taxanomies of services for persons with developmental disabilities classify respite care and related functions as follows:

<u>GSS</u>

Support Services
  Individual And Family Support
    Respite Care

<u>NASMRPD Provider Perspectives</u>

Family Support Services
Adaptive Living Arrangements
  Sitter Service
  Respite Care
  Homemaker Services
Social Skill Development
  Family Life Education and Counseling

NASMRPD Consumer Perspectives

Family Support Services
Parent Relief
Respite Care
Sitter Service
Social Development
Homemaker Services
Family Life Education and Counseling

AC/MR-DD

Alternative Living Arrangements
Homemaker And Sitter/Companion Services
Temporary Assistance Living Arrangements
Surrogate Family Services
Individual Program Support
Family-Related Services
Home Training Services
Family Education Services

These taxanomies generally emphasize respite care as a temporary living arrangement as a component of an individual and family support service.

CONCEPTUALIZATION OF THE SCOPE OF RESPITE CARE SERVICES BY ITS ADVOCATES

This respite care project was initially operated by the Center For The Development Of Community Alternative Service Systems (CASS) of Omaha, Nebraska. Their conceptualization(4) of respite care goes well beyond the traditional classification of respite care as a temporary living arrangement. CASS defines respite care as "supportive family interventions" and emphasizes the importance of "comprehensive supportive family services which are developed in response to a family's specific need." The CASS model community respite services system involves "supportive family-centered services ... offered in or out-of-the home ... (with) short-term timelines (but) on a regular or intermittent basis..." Thus, the concept of relief, i.e., respite, no longer is connotated with emergencies, crisis, and temporary living arrangements but with "concrete specification of tasks and responsibilities" planned through intervals of service.

Many states are now studying and funding on a pilot basis "respite care." In a recent study by Provider's Management, Inc.(5), the following national generalization was presented, "It is safe to say that respite care is a new, developing and emerging service for the developmentally disabled, and is far from being fully developed and regulated in any state. In fact, as the project staff has learned what other states are doing, it has become clear that Massachusetts has one of the most extensively developed respite care networks."

The state of Massachusetts currently defines respite care(6) as "temporary in-or-out-of-home care provided to a client for up to thirty days for the purposes of providing the family with relief, whether during emergency or planned periods, from the daily responsibilities of caring for the client; provided, however, that such care may be extended beyond thirty days if agreed to by the provider, the family, and where

appropriate, the client." In Massachusetts, the concept of respite care appears to go beyond the traditional concept of an alternative living arrangement but does not incorporate the CASS model of comprehensive supportive family services.

Maryland is considering the development of a respite care program(7), defined as "short term care, including in-home care, of individuals with a developmental or other handicapping condition, including the provision of temporary relief to the individual or individual's family." Again, like Massachusetts, the concept of respite care goes beyond the actual living arrangement but is not as comprehensive as CASS.

Many states are developing respite care programs but it does not appear that any have defined respite care as comprehensive supportive family services. Rather, it appears that respite care is seen as one component of a family support network. This practice is consistent with the nationally recognized service taxanomies discussed earlier.

THE NATURE OF FEDERAL FUNDING AND THE CLASSIFICATION OF SERVICES

Publicly financed services are generally of two types(2) - "generic services," defined as programs or activities available to and needed by a broader segment of the population, but from which persons with developmental disabilities may benefit (e.g., education, Medicaid, Title XX Social Services); and "specialized services," defined as programs or activities specifically designed to meet the needs of developmentally disabled persons (e.g., Developmental Disabilities, state and county mental retardation programs).

Services may also be classified as direct or indirect(8). "Direct services" are those provided directly to the client whereas "indirect services" are those provided to others (parents, teachers, employers, etc.) who have an effect on the lives of the client. The university researchers who amplied on this concept classified "family support services" such as parent education and training, in-home sitter services, out-of-home respite care, and homemaker services as indirect services.

Federal funding trends for programs serving the disabled may be generalized as (1) declining, (2) generic, and (3) direct(9). The Advisory Commission on Intergovernmental Relations (ACIR) in its May, 1979 report, Significant Features Of Fiscal Federalism, 1978-1979 Edition, estimates that federal aid as a percent of state-local expenditures is declining from a peak of 26.7% in 1978 to 25.4% in 1979 to an expected 23.6% in 1980. Cited as causes for the projected decline are a drop in the funding of temporary economic stimulus programs, overall budget restraints as part of the effort to slow inflation, and the growing strains on the fiscal resources of the federal government(10). Faced with Proposition 13 - like tax reduction/service reduction/tax spending restraint measures and the declining federal role, new federal initiatives during the next few years are unlikely.

Generic funding programs, based upon the idea of an entitlement to service (discussed later) are increasing. Given the declining federal role and the increase in generic funding, specialized (or categorical) programs are decreasing. Robert Gettings (11) has outlined five implications for the disabled given this increasing reliance on generic programs:

(1) A tremendous growth in federal dollars to persons with developmental disabilities has occurred.

(2) The statutory authority for generic assistance programs generally have nothing to do with the programmatic goals for persons with developmental disabilities. A substantial amount of Washington representative time (such as the UCPA Governmental Activities Office) is devoted to eliminating instances in which the funding authority works at cross purposes with programmatic goals.

(3) Utilization of generic assistance programs require a joint action by a number of state and/or local agencies to put funding packages together.

(4) Eligibility for one program frequently means eligibility for other programs; for example, the loss of SSI frequently results in the loss of Medicaid.

(5) Utilization of generic assistance programs result in strengthening state responsibility for plan development, service priorities, and eligibility parameters.

The budget restraints are more likely to significantly affect categorical programs than generic programs. For example, during the next 3-5 years the Rehabilitation and Developmental Disabilities programs are likely to constitute only a miniscule portion of the dollars needed to substantially expand and improve independent living services to developmentally disabled persons. According to Gettings, if expansion is to take place a number of activities must occur:

(1) Generic service programs must be better utilized.

(2) Service expansion must be built upon existing service systems, not new ones.

(3) There is an overriding need for cooperative agreements to spell out areas of responsibilities by mutually reinforcing roles.

(4) Given the fiscal constraints and wide ranging service needs, priorities will have to be established.

(5) The initial key to success of any nationwide effort is action by state government.

These predictions based upon an analysis of federal funding trends caution the reader not to expect the development of a new federal categorical program for respite care or family support services during the next several years.

Where expansion does occur, it is probable that it will occur around direct services, not indirect services. Federal manpower training program budgets have been devasted during the past few years; likewise, federal research efforts have been fortunate to merely stabilize. Growth in federal programs has occurred where people are entitled to benefits (e.g., Medicaid, Medicare, Supplemental Security Income, P.L. 94-142 education for all handicapped children).

Frank Laski(12) defines entitlement to service as existing when two conditions are met: (1) There exists a definable duty on the part of ascertainable service providers to give service to a particular person (or persons in general); (2) The persons

who are the beneficiaries of the duty have a legal remedy which they can use to enforce performance of the duty, or collect damages for failure to perform. (3) Without both conditions, the duty and the capacity to enforce the duty, there is no entitlement. A developmentally disabled person may demand the service, his family may buy the service if they can afford it, they may claim a moral obligation exists to provide the service. But without the two conditions - the duty and the capacity to enforce the duty - there is no entitlement.

A SUMMATION OF ARGUMENTS

Before presenting specific suggestions for financing respite care services, it is appropriate to summarize the arguments and logic presented so far in this paper.

(1) Nationally recognized taxonomies of services for persons with developmental disabilities generally emphasize respite care as a temporary living arrangement as a component of an individual and family support service.

(2) Certain respite care advocates have suggested that respite care be viewed as a comprehensive supportive family services network.

(3) Many states are developing respite care programs which may be viewed as one component of a family support network.

(4) Federal aid as a percent of state-local expenditures is declining with the resulting expectation that new federal service initiatives during the next few years are unlikely.

(5) Where growth is occurring in federal programs, it is generally happening in generic programs based upon an individual entitlement to service.

FINANCING RESPITE CARE MODELS

At its February 4-5, 1980 meeting, the CUNY/UCPA respite care advisory panel formulated the following definition of respite care: "Respite care is one component of a family/caregiver support system that provides temporary relief for primary care givers. It cannot function in isolation of other support services. It should be recognized that many other services provide relief but it is not their primary function. Respite care programs should not operate independently from a case management system."

The Massachusetts study cited previously (5) concluded that both community providers and local agencies "noted lack of funding as the major obstacle" to acquiring and delivering respite care. Providers cited as their second major obstacle the lack of knowledge of what funding sources are available. One reason for this is the diversity of definition of respite care. Another reason is the general lack of federal funding and the reliance to-date on state funding. This trend-reliance on state funding - is likely to remain for several years.

• Out-Of-Home Residential Placement

The traditional view of respite care (and the narrowest interpretation) has been temporary out-of-home placement in a residential facility.

The UCPA of Central Maryland (Baltimore) respite care program began as an effort to locate beds in residential facilities. Agreements were negotiated with the Mt. Washington Pediatric Hospital and St. Vincent's Child Care Center with backup arrangements because of diverse geographic needs at several nursing homes. For persons 18

years or older or low income children, financing occurred through the Title XIX Medicaid program. For other families, a sliding scale of fees based on income is established with the remainder subsidized by a state Developmental Disabilities grant, a state Mental Retardation Administration grant, and UCP of Central Maryland funds. Though the UCP program began as an out-of-home residential placement program, there has been less and less facility placement and more and more utilization of in-home and alternative family/respite care worker placement(13).

Likewise, the Childcare Assistance Program for Special Children (CAPS) referral service for respite care began as a cooperative effort with the Northern Virginia Training Center for the Mentally Retarded, a state regional, residential facility in Fairfax. Approximately 50% of CAPS' funding comes from state and local matching funds under the Mental Health and Mental Retardation County Boards with other funds from service organizations and the local Association for Retarded Citizens. More and more respite care is in-home or private respite parent home oriented rather than filling empty beds at the Northern Virginia Training Center(14).

The Massachusetts study(5) identified the reservation and utilization of beds in existing community residential facilities, pediatric nursing homes and hospitals, and state residential facilities as models of respite care currently in operation in the state. The funding of these programs comes from the Title XIX Medicaid, Title XVIII Medicare, and Massachusetts Multiply-Handicapped Children's Program administered through the Departments of Mental Health, Public Health, and Public Welfare. The Multiply-Handicapped Children's Program is a totally state financed program; in order to receive services through this program a child must be in need of nursing services (15).

The use of respite beds within existing state or private residential facilities is typified by the New Haven Regional Center, Connecticut and State Regional Retardation Center, Fergus Falls, Minnesota(14).

Increasingly, respite group homes, whereby a private home is available, on a 24-hour basis, for respite care are being developed. These facilities generally operate as traditional group homes with house parents or house counselors. Examples of these facilities are the ones operated by St. Christopher's Hospital for Children, Philadelphia, PA.; The Big "R" Respite Home, San Rafael, CA.; and the Respite Care Program, Columbus, OH.(14). These are state funded programs, usually through the state mental retardation authority(14)(16).

The primary federal funding sources supporting out-of-home residential placements appear to be:

(1) Title XIX Medicaid

Federal grants are made to the states under Title XIX of the Social Security Act to help states pay for health care services for low income persons. Inpatient hospital services and skilled nursing facility services are mandatory services each state must provide. States may receive federal matching to provide intermediate care facility services. Provision of medical services to recipients of Aid to Families With Dependent Children (AFDC) and Supplemental Security Income (SSI), known as the "categorically needy," is mandatory; states may provide services to others as they choose. States may not arbitrarily deny or reduce services to an otherwise eligible individual solely because of a diagnosis or type of illness or condition. The program is administered by the state Medicaid agency which is usually the state welfare or health agency.

States may receive federal matching for reserving beds during a recipient's temporary absence from a skilled nursing facility (SNF) or intermediate care facility (ICF)(17). On September 16, 1977 HEW removed all restrictions on specific time limits for such absences; however, states may apply whatever restrictions they choose except that every resident's plan of care must provide for absences other than for hospitalization. The reservation of beds policy has two immediate implications for the developmentally disabled. First, it allows residents to leave the facility and experience activities in a less structured setting. Second, it results in open facility beds which are being paid for already and thus offers a respite opportunity at little cost to non-Medicaid eligible persons.

(2) Title XVIII Medicare

Federally financed health insurance protection for Social Security recipients is authorized under Title XVIII of the Social Security Act. The Part A hospital insurance program covers inpatient hospital and skilled nursing facility care. Intermediate care is not covered by either the Part A nor Part B medical insurance programs. Medicare is a federal program offered everywhere in the U.S. through the local Social Security office; however, its benefits are limited and only disabled recipients of Social Security are eligible for benefits.

(3) Crippled Children's Services

Title V of the Social Security Act authorizes federal grants to the states to extend and improve medical and related services to "crippled children" and children with conditions that lead to crippling. States have a great deal of flexibility in determining available services and income eligibility. The program is administered by the state Crippled Children's agency which is usually located in the state health department.

(4) SSI Disabled Children's Program

P.L. 94-566 required that all disabled children receiving SSI payments under Title XVI of the Social Security Act be referred to the state's Crippled Children's agency or another agency designated by the governor. Disabled children under 8 years of age who have never attended public school are to be provided necessary medical, social, developmental, and rehabilitation services.

(5) Maternal And Child Health Services

Title V of the Social Security Act also authorizes federal grants to the states to reduce infant mortality and the incidence of handicapping conditions and to improve the health of mothers and children particularly those children with handicapping conditions. Medical and intensive nursing care are authorized services. Like the CCS program, states have a great deal of flexibility in determining available services and establishing income eligibility. Like the CCS program, MCH is usually located in the state health department.

(6) Summation

Out-of-home residential placement of a temporary nature is available for severely disabled adults under the Medicaid and Medicare programs and for disabled children under the Medicaid, Medicare, CCS, SSI Children, and MCH programs. Individuals with modest amounts of resources will be hindered under the Medicaid

and SSI programs. Medicare offers the least flexibility and availability of services. It must be stressed that states have the authority to develop respite care placements in facilities under these state administered programs.

- Out-Of-Home Family Placement

The use of private respite parent homes or foster parent respite homes whereby families provide temporary care for children and adults in their own home is another model of respite service. This model is currently operated by the Hartford Regional Center, Newington, CT. and the Johnson County Mental Retardation Center, Shawnee, KS.(14). The Massachusetts study(5) identified two similar models currently operating in that state - the respite placement agency which matches a client family with a particular community provider, including families, and the private respite provider which involves a nurse who opens his/her own home to provide overnight respite care for children requiring medically oriented services. The UCP of Central Maryland program(13) currently emphasizes the use of families or trained respite care worker's own home.

All these services are generally financed by state agencies as alternatives to their institutional budgets. For example, Massachusetts grants $350 per month plus specialized training to couples and single persons willing to share their homes with mentally retarded children(18).

The primary federal funding sources of potential in supporting out-of-home family placement include:

(1) MCH,CCS,SSI Children's Programs

Though this writer knows of no out-of-home family placement respite care service currently financed through MCH,CCS, or the SSI disabled children's programs, these programs contain the flexibility for short-term financing if states build respite care into their package of necessary services.

(2) Title IV-B Child Welfare Services

Title IV-B of the Social Security Act grants federal funds to the states to establish, extend, and strengthen services provided by state and local welfare agencies for the development of prevention and protective services which will prevent the neglect, abuse, exploitation, or delinquency of children. The program, usually administered by the state social services or welfare agency, delivers services to people in need without regard to financial criteria. Each state decides what services it will make available. The program currently finances foster care, adoption, in-home child care, and out-of-home child care. Though states have complete flexibility in administering this program, traditionally the program has been used for child care related services for AFDC families.

(3) Title XX Social Services

Social services under Title XX of the Social Security Act is a very broad supportive services program which can finance emergency shelter, foster care, and respite care as service categories currently recognized as allowable services. The law prohibits the payment of room and board except in emergency situations and medical services which are available under the other federal programs. Thus, out-of-home family placement as respite care must be defined from the perspective of services provided rather than from a room and board orientation.

People on SSI or AFDC must receive at least one Title XX service and people whose income is less than 80% of the state's median income may receive free services if specified in the state plan. States must charge fees to persons whose income is between 80-115% of the state's median income.

Title XX, because of its flexibility, is always the first service looked to for non-medical, non-education, and non-income maintenance supportive services. However, the program has operated under an annual appropriations ceiling since 1975. Though the ceiling raises slowly, most states are already spending at the ceiling. Thus, the development of new programs generally means the taking away of services from someone else.

(4) Volunteer Services - ACTION

The ACTION agency funds two volunteer programs - VISTA, Volunteers In Service To America, and FGP, Foster Grandparent Program - which could be tailored to partially meet out-of-home family placement respite care.

VISTA volunteers work to improve the health, education, welfare, or related problems of low-income communities. All VISTA volunteers must have a sponsor which plans and manages a project and provides the support needed, including supervision and training, to achieve project goals. ACTION recruits, trains, and places VISTA volunteers and provides them a living allowance. A respite care project could sponsor these volunteers to provide services in their home.

The FGP provides part-time volunteer service opportunities for low-income persons aged 60 and over to render supportive person-to-person services to children having special or exceptional needs. Sponsoring organizations supervise foster grandparents while ACTION provides stipends, daily meals, transportation, and physical examinations.

(5) Summation

Out-of-home family placement is growing in popularity. Titles XX and IV-B services seem the most logical choices for federally assisted programs. Efforts should be made to utilize the MCH, CCS, and SSI disabled children's programs. Lastly, several of the ACTION volunteer programs have potential. The thrust to-date, however, seems to be state funding as an alternative to the institutional budget.

- In-Home Health And Attendant Services

Almost all newly developed definitions of respite care specifically include "in-home care." The adequacy of federally financed home health and attendant services is a current public policy issue being considered by the Congress.

Homemaker and home management services are discussed in a subsequent section of this paper. Medically oriented home health services for the developmentally disabled generally include such activities as bowel and bladder programs, changing bags and other devices, skin care, turning and lifting support, and oral medication supervision. Attendant care services generally include getting the individual in and out of bed; giving baths, showers, and shampoos; combing, brushing, and setting hair; and dressing and undressing the individual(19).

The special needs of persons with developmental disabilities have not received adequate recognition in authorizing legislation or in subsequent regulations issued

by HEW concerning the delivery of home health services under Medicare and Medicaid. While the elderly and medically indigent have been specified as target groups for home health services, and the funds allocated preferentially to catchment areas in proportion to the numbers of elderly and medically indigent they contain, no similar provision has been made for persons with developmental disabilities, although it is obvious that they would constitute prime, ongoing consumers of such services. As a result the availability of a home health agency serving persons with developmental disabilities is contingent upon the geographical accident of their residing in an area in which large numbers of elderly or medically indigent individuals are present(19).

A corollary problem is that of inappropriate service options, including both the lack of those services of greatest utility to persons with developmental disabilities, and the unavailability of home health personnel outside the traditional 8AM.-5PM. work day. Thus, for example, while an individual with cerebral palsy might only require personal care services early in the morning and before retiring at night, he or she might well be unable to find a home health aid available to deliver services at those hours. Similarly, the services delivered by home health agencies are generally geared more toward acute than chronic care, resulting in an overabundance of skilled nursing personnel and a relative shortage of paraprofessional aide/attendant service(19)(20).

Medicare and Medicaid are currently structured to make it much easier to obtain in-patient services in a medical facility than in a noninstitutional setting. Benefit structures and federal matching rates provide incentives for the continued development and expansion of institutional services. These problems have been fully documented in the U.S. Government Accounting Office 1977 report Returning The Mentally Disabled To The Community: Government Needs To Do More, in the Congressional Budget Office 1977 report on Long-Term Care For The Elderly And Disabled, and in the various draft reports and proposals of DHEW's Task Force On Deinstitutionalization between 1977 and 1979(19).

(1) Medicare Limitations(19)

Medicare is by far the largest third-party payor of home health services yet the program contains numerous restrictions on home health care which effectively excludes a large proportion of developmentally disabled persons, particularly those requiring home based services. These limitations include:

a) Three-day prior hospitalization requirement;

b) Benefit period requirement whereby services can only be offered within one year of a hospital or skilled nursing facility stay;

c) Condition-related requirement whereby home health services can only be offered for the same condition for which the person was hospitalized;

d) Physician plan of treatment requirement whereby home health services can only be authorized by a physician;

e) One hundred visits during a year limitation; and

f) One hundred hour limit on personal care per month.

(2) Medicaid Limitations(19)

Most severely disabled adults are eligible for Medicaid by reason of their receipt of Supplemental Security Income and yet they remain ineligible for home health services because of the way Medicaid benefits are structured federally.

Medicaid regulations require that in order to qualify for home health services an individual must demonstrate a need for skilled medical care. Yet many persons with developmental disabilities do not need this advanced level of care in order to have their physical requirements appropriately met. The services of a home health aide, for example, might be sufficient for them to function optimally in a home environment. Under current restrictions, however, they would be barred from receiving home health care.

The great disparity among states in the types of home services provided under Title XIX creates considerable problems in attempting to monitor the quality of care on a nationwide basis. The problem is compounded by the fact that state licensure requirements for home health agencies vary widely, and as HEW has not yet required home health agencies to acceed to certificate of need regulations (whereby they would have to demonstrate the need for and quality of services provided in order to come into being or expand), there exist virtually no mechanisms for insuring the quality of services.

(3) Proposed Legislation(19)

UCPA and ARC have advocated the following recommendations for legislative change backed-up by administrative initiatives and adequate financing:

a) The federal government should make a national commitment to financing the promotion, development, organization, and delivery of home health services including specific recognition of the needs of the developmentally disabled as a primary target population.

b) The federal government should facilitate, in full partnership with all appropriate national interests, the development of a set of principles for home health services. Such a statement of principles should recognize the specific health care needs and home service needs of the severely disabled.

c) Home health benefits under Medicare and Medicaid should be broadened into a rational and effective national financing approach in order for developmentally disabled persons to receive needed and appropriate services. Such benefit changes should include:

1) Remove the requirement that home health care be predicated on the need for prior hospitalization, skilled nursing, occupational therapy, or physical therapy;

2) Limit allowances for home health care realistically in terms of hours of care provided rather than the number of visits allowed, thus permitting some daily care;

3) Specifically provide for coverage of personal care, including attendant care, subject to appropriate prescription and supervision in both Medicare and Medicaid;

4) Specifically allow coverage of occupational, physical, and speech therapy as qualifying services for home health services, subject to appropriate prescription and supervision in both Medicare and Medicaid;

5) Recognize non-profit community agencies which provide specialized services to narrowly defined populations (rather than global home health agencies which must provide comprehensive services to all persons) as Medicare/Medicaid home health service providers; and

6) Develop nationally recognized standards to insure service quality and appropriateness of care. Such standards, developed in full partnership with all appropriate national interests, should recognize the specific health care needs of persons with developmental disabilities.

(4) Possible Legislative Changes

On November 5, 1979 the House Committee on Ways and Means reported H.R. 3990, the "Medicare Amendments of 1979." The bill has been referred to the Committee on Interstate and Foreign Commerce which must report it prior to floor consideration.

H.R. 3990 would liberalize the Medicare home health benefit by: (a) allowing unlimited visits under both parts A and B, (b) eliminating the part B $60 deductible, (c) eliminating the present three-day hospitalization requirement under part A, (d) allowing occupational therapy as a home health benefit, and (e) liberalizing the eligibility of properietary home health agencies as providers. The bill would also require home health aides to meet certain qualification standards.

After five months of inaction, in mid-December, 1979 the Senate Finance Committee, in a surprise action, ordered reported H.R. 934, the Medicare-Medicaid reimbursement reform bill. This bill is intended to reduce health care expenditures; however, the Committee added the provisions of Senator Robert Packwood's (OR) bill, S. 1977, the "Medicare Home Health Amendments." The 100-visit limit on home health services would be eliminated and homemaker services, where not available under Title XX, would be allowed.

In the President's F.Y. 1981 budget recommendations, the Administration favors the elimination of the need for skilled nursing care as a prerequisite for home health services under Medicaid; it is anticipated that this proposal will increase Medicaid expenditures by $15 million. The budget also contemplates the elimination of coinsurance and the 3 day prior hospitalization requirement for home health benefits under Medicare with an anticipated expenditure of $194 million. The home health services demonstration program operated by the Health Services Administration ($6 million in 1979 and $5 million in 1980) is eliminated in 1981 because of these proposed Medicaid and Medicare amendments.

(5) Relationship To Respite Care

Even with enactment of H.R. 3990 and H.R. 934, home health and attendant care services will only be uniformly available to disabled Medicare beneficiaries and sporadically available to some Medicaid recipients.

The Title XX Social Services program has funded home health and attendant care services in relationship to residential services. However, Title XX can not fund services otherwise available under Medicare or Medicaid and it operates under an annual funding ceiling which does not yet hamper Titles XVIII or XIX.

An extensive in-home program is that administered by the Washington State Department of Social and Health Services(23). Home aid resources are available to developmentally disabled persons living in non-institutional settings for whom no other services/resources have been found available or appropriate. The implication of this program description is that the home aid resources program is fully state funded. The program finances support services on an extended basis to allow an individual to continue gainful employment, resource therapies, specialized equipment, parent-to-parent outreach, transportation, and respite care. Respite care is defined as "relief to parents or responsible persons providing care, from a 24 hour day, seven days a week involvement with an individual who is developmentally disabled." A maximum of 135 hours per family or 15 days per fiscal year is established. Given the inadequacies in federal financing of home health services, the Washington State program appears to be a carefully designed response to filling the gaps in federal funding. Respite care is one of several allowable services and its definition is narrowly constructed.

- In-Home Homemaker And Home Management Services

Increasingly, homemaker services are being viewed as important components to respite care. Homemaker services are offered by the following respite care programs - Johnson County Mental Retardation Center, Shawnee, KS.; Council for Retarded Citizens, Columbus, OH.; and Stepping Stones for the Handicapped, Cincinnati, OH.(14).

Homemaker services may be defined as general household management such as meal preparation, child care, and routine household care. Chore services may be defined as home maintenance activities such as repairs, yard work, shopping, cleaning, and personal care. Home management services includes instruction in child care, home maintenance, meal preparation, financial management, and consumer education. These three services - homemaker, chore, and home management - are fundamental Title XX services (22). These services are also available through the Title IV-B Child Welfare Services program. The nature, scope, and limitations of both Titles IV-B and XX have been previously discussed.

• In-Home Sitter And Companion Services

Next to out-of-home residential placements, the most traditional definition of respite care is the sitter/companion service. Sitter services are provided by individuals who are trained in caring for persons with special needs which provides relief to families allowing them to get away for a few hours, keep appointments, take an evening off, or have a weekend reprieve from providing continuous care to a family member.

The typical respite care agency for sitter/companion services sponsors the training and/or maintains the register of trained persons to link to families in need. The respite care agency is generally staffed by a volunteer or paid coordinator who has lead responsibility for administrating the program(24).

Examples of sitter/companion respite care programs are those operated by the San Diego County Association for Retarded Citizens(25); UCP of Central Maryland(13); Stepping Stones Center for the Handicapped, Cincinnati, OH(14); and Childcare Assistance Program for Special Children, Inc., Springfield, VA(14).

It is interesting to note that the UCP of Wisconsin report on respite care(24) declares that "there is little if any cost to this program as the parents will pay the sitter directly." The report does, however, recognize that the respite care coordinator "may need to be subsidized." A discussion of financing the start-up and core staffing of respite care programs follows in a subsequent section of this paper.

Potential federal funding sources for sitter and companion services includes the following:

(1) Maternal and Child Health Services

Refer to page 9 of this paper for a brief overview of this funding source.

(2) SSI Disabled Children's Program

Refer to page 9 of this paper for a brief overview of this funding source.

(3) Title IV-B Child Welfare Services

Refer to page 10 of this paper for a brief overview of this funding source.

(4) Title XX Social Services

Refer to pages 10-11 of this paper for a brief overview of this funding source.

(5) Volunteer Services - ACTION

Refer to page 11 of this paper for a brief overview of this funding source.

(6) USDA County Extension Service

The U.S. Department of Agriculture administers the Cooperative Extension Service to develop and provide educational programs and information to the general public in the fields of home economics, youth development, rural development, and agriculture(28). Funds are disbursed by the U.S.D.A. to land-grant universities and colleges and county extension services which have much flexibility in the use of funds. UCP of Northeastern Maine and the YWCA are working to develop a training program for respite care sitters with County Extension Service funds(26).

• Family Support Services

Rachel Warren has observed that "respite care programs, especially those which are in-home, will result in an increased awareness of other family and individual needs." This observation leads her to conclude that support services might include information, referral, follow-along, crisis intervention, counseling, transportation, parent training, etc.(27). The CUNY/UCPA definition of respite care cited previously attempts to clarify the relationship of family support services and respite care services. Respite care is viewed as one component of a family/caregiver support system which cannot function in isolation of other support services and must be linked to a case management system. Ms. Warren maintains that family support services are illustrations of programs with a relief function but that they should not be cited as respite care programs. The scope of comprehensive family support services is so great, that a separate paper on funding is required.

• Respite Care As Day Activities

The Massachusetts study(5) identifies group daytime activities programs as a respite care model, i.e., allowing daytime relief for the family. Rachel Warren's report(27) identifies day activities as illustrations of programs with a relief function; they are not respite care programs but they may offer respite services.

Examples of day activities currently being termed respite care follows:

(1) University of South Dakota(29)

The University Affiliated Program at the University of South Dakota operates a group home for developmentally disabled children who are undergoing extended diagnosis and evaluation during the nine month school year. During the summer of 1979, the UAP operated a "respite care" program for children not in school during the three summer months. Day activities with an emphasis on recreation was provided. The program was financed by the SSI disabled children's program with Title XX providing support for non-SSI children.

(2) UCP of Northeastern Maine(26)(27)

UCP of Northeastern Maine operates a summer camp program as "part of the respite care continuum" with financial support from Title XX Social Services.

(3) UCPA of New York City(27)

UCPA of New York City operates a summer family conference which offers intensive educational and counseling experiences for families. A day camp and evening sitting services are emphasized.

(4) UCP of Winnebagoland, Wisconsin(27)

UCP of Winnebagoland operates "respite care weekends" where once a month socio-recreational activities are provided at various university dormitories, seminaries, and camps.

START-UP AND CORE STAFFING OF RESPITE CARE PROGRAMS

The previous section on respite care models has emphasized the financing of services involved in operating a respite care program. It is generally assumed that all of these programs require a full-time staff member to develop, administer, and coordinate respite care services.

Estimates of necessary operating budgets differ somewhat from locality-to-locality. Two examples are cited below.

CAPS, Springfield, VA.(14)

Personnel Services

Director/Registrar (20-hours a week) (includes CAPS' share of F.I.C.A.)	$5,660

Operating Expenses

General repair of equipment	150
Professional services (auditor, consultant)	200
Travel, routine, @ 14¢ a mile	160
Travel, conference & convention, @ 14¢ a mile	75
Postage and stamps	360
Telephone (business phone in private home)	262
Printing (brochures, xeroxing)	150
Office supplies	275
Educational supplies (pamphlets, books)	50
Office equipment	110
Educational equipment	75
Insurance (Corporation), Treasurer Bond	120
Dues, memberships, subscriptions	50
Subsidized care (for families needing respite)	1,325
Total Operating Budget	$9,022

UCP of Wisconsin(24)

Personnel Services

Half-time Director/Coordinator (20-hours a week)	$5,000
Fringe	1,250
Secretarial/Clerical (10-hours a week)	1,800
Fringe	450

Operating Expenses

Subsidized care (for families needing respite) (100 consumers x average 7 days each annually) cost for respite worker 20/day ($15-state; $5-consumer)	10,500
Relief Fund (assumption that 10% of families in need of respite care cannot pay $5/day)	350
Training	2,000
Telephone	250
Printing	150
Postage	250
Travel	3,570
Total Operating Budget	$25,570

The major difference between the two examples is the addition of subsidized care in the Wisconsin model. These expenses should be considered as services rather than core staffing.

Potential funding sources include the following:

(1) Developmental Disabilities

Probably the most catalytic of funding programs has been the federally assisted, state operated Developmental Disabilities program. Federal funds are used to assist states in developing and implementing a comprehensive and continuing plan for identifying and meeting the needs of developmentally disabled persons and in providing funds to help meet a portion of these needs through service initiation and demonstration programs.

UCP of Wisconsin has received a two year Developmental Disabilities grant to study respite care and convince at least 10 community service boards to establish and/or fund respite care programs during fiscal year 1980(30). The UCP of Central Maryland respite care project was initiated with a DD grant(13). The excellent Massachusetts study was financed by a DD grant(5). And this national respite care study is being financed by federal DD funds.

(2) State Funds

Although DD seems to be the catalyst in initiating these programs, it is state funds that have continued the initiative. It is state funds which are likely to provide stable financing for respite care core staff.

The UCP of Central Maryland project is now financed through a state Mental Retardation Administration grant(13). The Virginia CAPS program is largely financed by the state/county MH/MR boards(14).

Wisconsin uses local Unified And Developmental Disability Boards and Departments of Social Service funds for its respite care programs. Currently $490,000 is identified in the state budget bill for respite care programs for 1980-81 and to be administered through the 51 local boards(24). The Maryland Department of Human Resources has drafted state legislation to require that agency to develop and implement respite care services programs for developmentally disabled persons(7).

(3) Volunteer Services - ACTION

Page 11 of this paper discusses the VISTA program and its potential for staffing a respite care program.

(4) CETA(31)

The Comprehensive Employment And Training Act (CETA) is designed to provide employment opportunities for various segments of the population which are found to be economically disadvantaged. There are several different types of programs; in general, several billion dollars a year are allocated to roughly 400 units of local government to operate manpower training programs. At least 30 UCPA affiliates have CETA supported staff. UCP of Northeastern Maine has recently made application to CETA to hire a "respite care resource integration coordinator"(26).

(5) Title IV-B Child Welfare And Child Abuse Projects(32)

P.L. 93-247, the "Child Abuse Prevention And Treatment Act," authorizes federal assistance to train professionals and paraprofessionals in identification and treatment techniques, to develop and implement standardized reporting systems and case-finding mechanisms, to provide technical assistance for the development of identification and treatment programs, and to fund special projects in the field of child abuse and neglect. The program is administered by the federal Office of Child Development.

The Title IV-B Child Welfare Services program is discussed on page 10 of this paper. In Wisconsin, Child Abuse and Neglect monies and Child Welfare Grants have been used to start up respite care programs for children in several counties, such as the Respite Program at Marshfield's Comprehensive Child Care Center in Wood County, and the Respite Emergency Crisis Center in Dane County. Announcements for requests for proposals (RFP's) are generally distributed through the regional offices of the Division of Community Services(24).

CONCLUSION

Public policy makers design programs and establish arbitrary boundaries around them inorder to have workable funding guidelines and parameters and insure accountability, integrity, and control. This fact of public financing implies that respite care should be narrowly defined so it is understandable and operational. To define respite care as all services required by families not currently being offered, ignores the potential and mandates of existing programs, creates confusion regarding its mission, and implies uncontrollable budgetary implications.

Nationally recognized taxanomies of services for persons with developmental disabilities generally emphasize respite care as a temporary living arrangement (both

in-home and out-of-home) as a component of an individual and family support service. Many states are developing respite care programs which may be viewed as one component of a family support network.

Federal aid as a percent of state-local expenditures is declining with the resulting expectation that new federal service initiatives during the next few years are unlikely. Where growth is occurring in federal programs, it is generally happening in generic programs based upon an individual entitlement to service. It appears that however respite care is defined, utilization of generic programs will be the key to success.

There is one possibility of a federal categorical response to funding respite care. P.L. 95-602, the "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978," targets federal DD funds to the states on four national priority services - case management services, child development services, alternative community living arrangement services, and nonvocational social-developmental services. These services were prioritized because they were determined to be among the most difficult services to fund federally. If Congress continues the DD program in 1982, it is likely that the priority service approach will also be continued. Respite care and/or family support services, if it can be documented that these services are extremely difficult to fund, could be a nationally recognized DD service priority. However, this is a temporary solution since DD funds are short-term funds. The long range solution to this issue is to liberalize the generic funding programs so that respite and related family support services may be financed. Even if this occurs, eligibility will continue to be determined by an income test.

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